Summary Report for TASH Project – June 2015

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EXECUTIVE SUMMARY

The Talk About Self Harm (T-A-S-H) project initially commenced as a one year scoping study once funding was confirmed in January 2014. Ethical approval was granted in October 2014 and the project has continued to run until June 2015 as agreed with the commissioners.

The study was founded on the premise that early detection and improved services to children and young people with mental health needs and self-harm presenting to primary care would afford significant benefits in health and wellbeing outcomes and cost savings to the NHS in the longer term.

Self-harm has become a major public health concern with studies estimating between one in twelve and one in fifteen children and young people self-harm although the literature presents a complex picture of the relationship between mental health and self-harm and many studies conflate self-harm as a coping strategy with suicide or attempted suicide.

The project employed a Participatory Action Research (PAR) design previously tried and tested by the Principal Investigator (PI) working with women who self-harmed in custody. From our reviews of the literature to date this is the first time PAR has been used with young people who self-harm and present to primary care.

The project has been through a number of PAR cycles in the identification, development and refinement of the initiatives relating to improving the use of self-management strategies with young people who self-harm. To meet the project's aims, five different work packages have been undertaken:

1. Stakeholder engagement
2. A scoping review of the literature
3. A baseline audit of primary care patient records
4. Qualitative focus group interviews with stakeholders
5. Coaching/training interventions with primary care staff

Three GP practices were purposefully selected to take part in the study because they were linked to the two universities in Nottingham and therefore offered the best possible chance of recruiting young people to the study who were in the age range of 16-25 and who had experience of self-harm.

Wider stakeholders engaged with the study through a Project Advisory Group which enabled access to young people with experience of self-harm who subsequently took part in the project.

A self-selecting sample of young people with experience of self-harm came together through a snow ball sampling approach. We had good reason to assume that this group of young people could be considered 'representative' of the young people attending the GP surgeries with self-harm as several of them were at University already or aspired to go onto University after their college courses were completed.

Key findings against expected outcomes are:

- An audit of young people attending the thee GP surgeries revealed 296 who had a primary clinical code for self-harm. Of these 296 young people, 86 were male and 210 were female.

- The 296 young people in the audit sample equated to 649 events relating to both physical acts of self-harm and thoughts about self-harm; of which 171 events were not given a specific clinical code. The average number of events for the young people was 2.2. The most frequently occurring number of events of self-harm across the sample was 1.

- The number of young people's records coded for suicide/attempted suicide was small. Overdoses comprised 25% of the events and the largest proportion of events were either coded as intentional self-harm or self-harm with sharp object.

- 4.4% of the young people had at least one episode of self-harm when they were under the age of 16.

- Young people tended not to present to primary care with self-harm. They had mixed views about presenting to their GP's surgery and would usually talk to friends and family. They would approach their GP if they needed medication.

- Practice Nurses tended to see young people for appointments where self-harm became apparent rather than being the presenting problem. Usually this was because Practice Nurses were undertaking other procedures such as taking blood and self-harm injuries were revealed.

- GPs reported seeing young people if their method of self-harm included an overdose.

- All young people who took part in the study said that they felt that they personally had benefited from their involvement in the project. These benefits varied from feeling that they were genuinely helping others as well as helping themselves not to self-harm.

- The coaching intervention was tailored to the different needs of each of the three practices. GPs and Practice Nurses in one practice chose to receive the coaching in separate groups but in the other two practices they came together.

- The coaching was supported by packs of self-help materials that young people selected as being the most helpful from their experience. Practice Nurses and GPs are using the self-help materials in their consultations and we plan further follow-up events to evaluate how this is progressing.

- The report concludes by asking whether primary care is the best place from which to offer self-help approaches to young people who self-harm and if not then how can preventative health care for young people be commissioned differently. If as young people say they seek help firstly from family and peers might self-help be better promoted through schools, FE colleges and youth services.

- Further thought needs to be given to the issue in terms of whether a longitudinal study of self-help for young people who self-harm compares self-help offered through different outlets with primary health care being just one of these.

BACKGROUND TO THE PROJECT

Young Peoples' Mental Health

Improving young people's mental health and wellbeing has become increasingly important in recent years and one of the reasons for this is to alleviate the burden of ill health in this age range thereby reducing costs in the longer term. The British Child and Adolescent Mental Health Surveys in 1999 and 2004 found that 1 in 10 young people had a diagnosable mental disorder, (Meltzer et al 1999, Green et al 2005). Suhrcke et al (2008) highlight that mental ill health in children and young people is associated with excess costs of care falling to a variety of agencies including health, estimated between £11,030 and £59,130 annually per child.

The fact that mental ill health not tackled appropriately in childhood and adolescence can go onto last into adulthood, requiring a response from specialist and costly mental health services was highlighted by Kim-Cohen et al in 2003. They identified that more than half of adults with mental health problems known to services, were diagnosed in childhood, although many were not treated appropriately at that time (Kim-Cohen et al., 2003). This suggests that the significant numbers of young people who do experience mental distress need appropriate responses from youth friendly health care services and that when this happens, for example through early intervention, savings are achieved (Friedle and Parsonage, 2007). Similarly Knapp et al (2011) asserts that although there are no quick wins in relation to youth mental health interventions the impact of these and the scale of the potential "pay offs" means that costs are often fully recovered in a relatively short space of time.

The research and literature relating to youth mental health encompasses a broad spectrum of issues and conditions. Kim-Cohen et al (2003) equated mental health difficulties to diagnosis; however many young people may not be diagnosed with a mental disorder but nonetheless experience significant mental distress which can impact on their emotional and educational development as well as physical health and subsequent life chances (Sainsbury Centre for Mental Health 2009 and Goodman et al 2011). Whilst secondary/specialist services are unlikely to be appropriate for these young people we need to understand better what types of help are appropriate and where these sources of support should come from. Literature suggests that young people are more likely to seek help from their friends, their family and at School as well as through youth services, increasingly provided by the voluntary sector (Mental Health Foundation 2006; Young Minds & Cello 2012; MIND 2013, Spandler and Warner 2007). Support from peers and support organisations can be face to face and increasingly accessed through social media.

Young People and Self-harm

Of all the mental health issues young people experience, self-harm has become a major public health concern. Young Minds (2013) identify that between one in twelve and one in fifteen children and young people self-harm. However the literature presents a complex picture in terms of the relationship between mental health and self-harm. According the 2004 B-CAMHS survey (Green et al 2004) "the rates of self-harm in 5-10 year olds was 0.8% in those with no disorder, rising to 6.2% for those with anxiety disorder and 7.5% in children and young people with a diagnosis of conduct disorder, hyperkinetic disorders or less common disorders" (Reported in DH 2012, Chapter 10 page 3). Data from the ONS (Meltzer et al 1999) reveals that rates of self-harm were higher in children and young

people who were experiencing significantly more stressful life events, family discord and parental ill health.

The contribution of early childhood 'trauma' to mental health issues such as depression, anxiety, and personality disorders has been postulated by a number of studies (see Ringel and Brandell 2012). The body of research suggesting a further link between childhood trauma, mental distress and self-harm behaviour has been summarised by Connors (2000) although this relationship is complex and relies upon individuals who self-harm being able to recognize a relationship between their behaviour, past experience and coping responses (Tantum and Huband, 2009). For some individuals this relationship may remain unconscious, with their self-harm unexplained, and/or they may engage in self-harm for reasons other than coping.

The relationship between young people's self-harm and suicide is also complex and only partially understood. Many studies in the research literature do not differentiate between suicide and self-harm because of the complexities of establishing the intent that is driving the behaviour. According to Walsh (2012) someone who intends to commit suicide wants to eliminate their consciousness permanently while a person who self-harms is attempting to modify their consciousness to reduce distress or curtail feelings of dissociation in order to live another day. In a recent paper by Hawton et al (2015) self-harm is identified as an important factor for eventual suicide as between 50-60% of people who die by suicide have had a history of self-harm. However Hawton et al's study showed that the risk of suicide increased with age at the time of self-harm with the youngest age group (10-24 years) having the lowest risk of suicide despite being the biggest group in terms of numbers in the study. Hawton et al also found that the majority of study participants self-harmed by self-poisoning as distinct from those who hurt themselves in other ways. The numbers of individuals where there was a co-occurrence of self-injury and self-poisoning in comparison with the numbers who only used self-poising were low, suggesting that there may be some value in Walsh's approach to thinking about the difference between self-harm as a coping response and suicide or attempted suicide as a manifestation of intent to end consciousness completely.

Participants in Hawton's study (n= 40, 346 in total) made contact through Emergency Departments in three localities in England. So although the literature suggests that young people seek support informally from friends and family, often via the internet the point of contact at a time of crisis is likely to be with health care services (Spandler and Warner 2007). This raises the question of how health professionals engage with young people presenting with self-harm issues (McDougall et al 2010). The Mental Health Foundation (2012) calls for primary care colleagues to become as skilled at signposting and treating mental health related issues (including self-harm) as they are for physical conditions.

Tantum and Huband (2009) explore why individuals who self-harm are often tagged with the unhelpful "attention seeking" label and offer one reason for this as because they displace more deserving patients who are forced to go without health care because of time spent treating people who self-harm. The Mental Health Foundation (2006) found that young people in particular reported that their experiences of asking for help for self-harm often made their situation worse not better as many encountered hostile responses or ridicule from health care professionals. This is particularly worrying in the light of reports from Young Minds (2013) and the Mental Health Foundation (2006) which highlight that more children and young people are using self-harm as a way of coping with the pressures of day to day life such as exam stress, bullying, and family breakdown and are living their lives in the spot light of social media. This suggests that young people who self-harm would be better seen as "attention deserving" and helpful conversations used to engage them supportively.

The NICE guidelines modified in 2004 reflect this and assert the need for clinicians to treat people who self-harm with the same respect, dignity and choice as they would treat any

patient. The guidelines also call for the involvement of people who self-harm in the commissioning, planning and evaluation of services to support them. This is supported by Gilburt (2011) who asserts that service users can and should be involved in the risk assessment and management of self-harm and that the quality of the therapeutic relationship with the clinician is key to this.

Public Involvement/Self-help, Recovery and Participatory Action Research

The survivor movement in psychiatry has been instrumental in progressing a reform agenda in health services more widely which sees people who use services more involved in their planning and delivery (DH 2006). The recovery movement in mental health has redefined recovery as a process rather than being symptom free which hinges upon a 'negotiated' relationship between the service user and the mental health professionals who are involved in their care plans (see Bailey 2012).

However Ward et al (2013) identified that in relation to self-harm very few studies have attempted to involve service users in the evaluation of the effectiveness of psychosocial interventions for self-harm. Where they have it is the non-coercive relationship building with professionals as part of the self-harm intervention that seems to link with improved outcomes for service users in terms of reductions in the severity and frequency of self-harm. This chimes with the work of Gilburt, (2007). Ward et al call for new ways of thinking about self-harm in the way research studies are conducted as often service users do not consider cessation of self-harm to be a useful treatment target (Kelly et al., 2008). This finding is echoed by the Mental Health Foundation (2006) in relation to how young people define their recovery from self-harm. For some their goal is about stopping their self-harm completely, although this may not be an immediate goal, while for others recovery means reducing the severity and frequency of self-harm as young people tackle the underlying distress that fuels it by using distraction techniques or finding alternative ways of coping.

Over the past 15 years in the UK there has been a shift towards encouraging individuals to self-manage their conditions and a need to change the way systems work to support this effectively (Marmot, 2010). The Department of Health (2005) stated that supporting self-care can help to improve health and quality of life, leading to an increase in patient satisfaction and a decrease in the use of formal services. Self-management interventions range from structured face to face programmes to booklets and online resources which an individual can use independently.

The Principal Investigator (PI) on this project (Bailey) has previously demonstrated that the use of self-management strategies and self-help materials, developed in collaboration with those who will use them, can offer effective self-help to women who self-harm in custody. Women offenders who took part in the study reviewed self-help materials that were created by mental health service users who self-harmed (for example Arnold 1998) and adapted these to create self-care packs that were made available to all women in custody who reported thoughts of self-harm or engaged in self-harming behaviour.

The self-care packs included educational materials to help the women develop an improved understanding of what self-harm is and why people engage in it alongside care planning type tools based on Copeland's 1989 Wellness Recovery Action Plan (WRAP) that were designed to support the women to have helpful conversations with staff about how to manage their self-harm in better ways (Ward and Bailey 2011).

Women also designed training materials and used these in training sessions which they co-delivered to prison staff, assisted by members of the research team (Ward et al 2012). The project adopted a participatory approach involving women and prison staff in the project which was successful in improving outcomes for women in custody in terms of reducing the incidence and severity of their self-harm as well as reducing significantly the

health care costs previously associated with managing self-harm in the prison (Ward and Bailey, 2012).

Participatory Action Research with Young People who Self-harm

Given the findings of the research conducted by Bailey and colleagues and the wealth of literature on the importance of engaging young people in helpful conversations about their self-harm (Young Minds 2013, Mental Health Foundation 2006) the impetus for this study was to improve young people's influence over what constitutes these helpful conversations with primary health care staff. This seemed important to influence given the time limited nature of primary care consultations and the fact that GPs spoken to in the Mental Health Foundation's study said they did not know what language to use when talking to a young person about self-harm and also disclosed some negative attitudes towards those who self-harmed as manipulative and who they understood to be likely to commit suicide.

Given the success of the project in the prison setting it seemed likely that involving young people in the co-production of self-management materials to be used in primary care could facilitate better outcomes, in particular more effective relationships with primary care staff. In order to achieve the overarching ambition of the researchers which was to improve outcomes for young people who self-harm and present to primary care for support, a number of scoping and co-production activities needed to occur.

This project funded by Nottingham City Clinical Commissioning Group, aimed to complete this preliminary scoping and co-production work. In particular it aimed to:

1. Use the principles of Participatory Action Research (PAR) to engage with all relevant stakeholders, including young people and primary healthcare staff

2. To tailor the methodology used by Bailey in her previous study to make it fit for purpose for conducting research in a primary care setting.

3. Conduct a scoping review of the literature to identify the most recent evidence based self-help/self-management approaches for young people who self-harm.

4. Co-produce with relevant stakeholders self-help/self-management materials for use in primary care settings.

5. Audit the number of young people currently accessing primary care for support with self-harm behaviours including the number and nature of their presentations and what other services they accessed or where referred to via an audit of patient records.

6. Understand the experiences of primary care staff of providing healthcare interventions to young people who self-harm and the barriers and support systems young people experience when accessing primary care for support.

7. Conduct training/coaching interventions with primary care staff to support the use of self-help/self-management materials in the primary care setting with young people who self-harm.

8. Identify the barriers and support systems to using self-help/self-management materials within a primary care setting.

9. Identify the barriers and support systems when using PAR as a research methodology in primary care settings with young people who self-harm.

METHODS

The project adopted a Participatory Action Research (PAR) approach to engage young people and Primary Care staff as stakeholders in the research process to co-produce action towards change. Ward et al (2013) identify that those who produce research and those who will ultimately use it often inhabit different worlds. We were mindful that the research literature suggested this to be especially so for young people on the receiving end of health services generally and particularly health services in relation to self-harm. By bringing young people and health professionals in primary care together to jointly influence the research process, the innovations to be piloted and the outcome measures we anticipated that some of the barriers to the implementation of self-help management strategies in primary care practice would be reduced.

PAR as used by the Principal Investigator in her previous research involves a cyclical process of planning, action and critical reflection as illustrated in Figure 1.

Figure 1 - The Participatory Action Research cycle

The project has been through a number of PAR cycles in the identification, development and refinement of the initiatives relating to improving self-management strategies with young people who self-harm. To meet the project's aims, five different work packages have been undertaken:

1. Stakeholder engagement
2. A scoping review of the literature
3. A baseline audit of primary care patient records

4. Qualitative focus group interviews with stakeholders

5. Coaching/training intervention with primary care staff

Each of these work packages featured in one or more of the phases of the PAR process as the initiatives were introduced and reflected upon. Stakeholder engagement was a pivotal feature of the PAR process throughout and several of the work packages occurred simultaneously reflecting the action research process as iterative in nature. So for example as young people evaluated self-help materials in respect of which ones they favoured and how to use them, their feedback was shared with the GPs and Practice Nurses in the coaching sessions.

Taking each of the phases in turn we highlight below the key activities undertaken and methods used.

Phase 1 – Planning

The first month or so of the project was dedicated to:

- Clarifying the research design for the project (meeting with Paul Leighton on 13th February 2014)

- Visits to practices and initial scoping meetings/focus groups with GPs and Practice Nurses in each of the three practices to discuss with them and plan the coaching interventions and understand from their perspective the issues surrounding working with young people who-self harm

- Scoping of the self-help literature

- Networking with relevant stakeholders to identify young people who were willing to be involved in the planning stage of the project. This networking activity occurred through a snowball type approach led initially by Harmless who identified services and individuals they were in touch with in connection with their roles in offering support for self-harm and or suicide.

Out of this initial planning stage a number of actions developed which ensued in the first 6 months of the project including:

- Setting up a Steering Group with membership including the core research team (Bailey, Kemp and Wright), the practice managers from the three GP surgeries where the project was taking place and a local third sector organisation with relevant expertise in the area (Harmless)

- Involving a wider group of stakeholders as an Advisory Group who facilitated access to a group young people from Base 51 and Harmless

- Regular meetings between the PI and this group of young people who continued to meet throughout the project to develop the self-help materials as well as being involved in other ways; for example contributing their expertise to the design of the consent forms and participant information sheets for ethical approval

- Securing approval from relevant ethics committees and R and D approval (see Appendix 1)

- Further meetings and discussions with staff in the GP practices to ensure methods for data collection in terms of the audit of patient records would be feasible and timely

- Preparing the self-help materials for use within the practices and agreeing how the coaching interventions for staff would be delivered

Phase 2 – Action for change

Phase 2 of the project really began once ethical approval had been secured and was earmarked by a change of name for the project which occurred as a direct result of the young people's involvement. From this point onwards the project became known as TASH –Talk About Self Harm. During this phase young people from Harmless and Base 51 came together with the PI and colleagues 9 times. They developed a blog site for the project where they included what they considered to be helpful self-help resources for other young people with experiences of self-harm (see Appendix 2 or http://talkaboutselfharm.blogspot.co.uk/)

They also designed posters for use in the GP surgeries to bring the project to the attention of would-be participants who would be receiving information on self-help strategies from GPs and Practice Nurses.

During this phase the baseline audit of primary care records commenced according to the pro-forma attached at Appendix 3. This pro-forma was agreed with all three of the practice managers who undertook an initial search using agreed clinical codes to identify the population of young people within each practice who were presenting with self-harm. This baseline audit produced 296 records for young people across the three GP surgeries.

After the initial search the CI and PI spent time in each of the practices with administrative staff collecting further data in relation to 25% of the 296 young people. This 25% sample was selected randomly and the reason for doing this was to ascertain more detail about young peoples' typical journeys into primary care and onward referral as a result of their self-harm.

Attempts to recruit young people in each of the practices took place during this phase. The CI and PI offered drop in sessions and bookable one to one appointments to meet young people who were receiving care for their self-harm from the respective GP surgeries. Despite several attempts only one young person presented who opted not to be involved in the project.

Coaching sessions also commenced with GPs and PNs in two of the practices and the research team continued their networking with other similar projects in the area.

Phase 3 – Evaluation and Critical Reflection

Our evaluation of Phase 2 of the project was that our attempts to recruit participants in the GP surgeries had not gone as planned. In dialogue with colleagues from other similar projects such as e-DASH at the Institute for Mental Health at the University of Nottingham we learned that we were not alone in this. This led us to refine our methods for recruiting young people in the practices and the PI did further evaluative work continuing to meet with the young people at Base 51 on another 7 occasions.

During one of these sessions the PI ran a focus group with young people at Base 51 to understand in more detail why young people would be reluctant to present to primary care for help with their self-harm. The focus group questions were informed by emerging themes from the literature, comments made by young people when designing the blog site, discussing the project generally and from the initial scoping meetings/focus groups with GPs and Practice Nurses (see Appendix 4).

Instead of working with young people from the practices to review the self-help materials available this work was undertaken with the young people from Harmless and Base 51. Young people looked at the materials available and commented on which ones they

thought most helpful and why. This led to over 200 packs of a set of self-help materials being produced for use in each GP practice based on young peoples' feedback.

Also during this stage the PI undertook separate focus groups with young people at Base 51 to understand their experiences of being involved in the project so far. Focus group questions (see Appendix 5) were modelled on those used by Bailey in previous studies where service users had been involved in mental health research (Haswell and Bailey 2007, Smith and Bailey, 2010).

The coaching sessions continued with the GPs and Practice Nurses as the self-help packs were disseminated. This allowed for some initial and informal evaluation of their content.

Further planning and actions that arose out of the first phase of evaluation and critical reflection was that the young people designed a poster to present the study at a local conference on young people's mental health (see Appendix 6). GPs and Practice nurses started to use the self-help materials in their practice.

Our plans for a further evaluation of the way these materials are being used have been agreed with the Steering Group and will take place during meetings with GPs and Practice Nurses as part of the next stage of the project which will focus on gathering further data and more in-depth analysis of data already collected to inform the writing of a project proposal for NIHR funding.

Sampling Issues

The three GP practices that were involved in the study were purposefully selected following dialogue with colleagues in the research design service. Initially the research team had intended to sample more GP surgeries but because of the focus of the study on young people it was decided to focus on GP surgeries where we could be certain that young people would feature in the practice population. The three GP practices were linked to the two local universities and therefore offered the best possible chance of recruiting young people to the study who were in the age range of 16-25 and who had experience of self-harm.

Young people who took part in the focus group interviews at Base 51 were a self-selecting sample. As we expected they came together through a snow ball sampling approach whereby once a handful of young people attended for an initial meeting about the project they encouraged others with similar experiences of self-harm to come along. We had good reason to assume that this group of young people could be considered 'representative' of the young people we might recruit through the GP surgeries as three of the young people were already studying at the universities to which the GP surgeries involved in the study were attached. Another young person was studying at another university in the region and several other young people were aspiring to go to university once their college courses were complete.

Similarly GPs and Practice Nurses who took part in the coaching sessions were also a self-selecting sample. In one practice GPs and Practice Nurses opted to receive the coaching intervention as two separate groups whilst in the other two practices the coaching sessions involved GPs and Practice Nurses together. As the thrust of the coaching intervention was determined by the needs of the staff in each practice the approach and content differed, although took an overarching focus on supporting the staff to have helpful conversations with young people with self-harm to help them to manage this in better ways.

Our initial expectation was that we would work with a member of the primary health care team as a self-harm 'champion' in each of the GP surgeries. However all practices opted to receive the coaching intervention as a team. In one practice a GP was clearly taking the lead in self-harm as this was his particular area of clinical interest and he attended the

focus groups with GPs and with the Practice nurses as well as providing a training session on the topic of self-harm for the whole practice team.

Data Analysis

During each phase of the PAR process a variety of data was captured. This included statistics relating to the audit process and narratives from the focus groups. Informal discussion and feedback took place during the meetings with young people, with GPs and Practice Nurses and during the coaching sessions.

The audit data was analysed using simple statistics and further more detailed analysis of young peoples' journeys into and onward from primary care will be undertaken during the next stage of the project. The focus groups conducted with young people and primary healthcare staff were transcribed verbatim and subject to thematic analysis. This involved the researchers in reading and re-reading the transcripts to identify key themes and sub-categories within the narratives.

FINDINGS

Stakeholder Engagement

Since the start of the project the Steering Group has met on 5 occasions and the PAG on three. The terms of reference for these two groups are provided in Appendix 7.

The CI and PI held a number of stakeholder engagement meetings in each of the three GP surgeries to raise staff's awareness of the project, find out about the issues they were encountering in relation to young people presenting with self-harm and plan the coaching intervention. The number of meetings and details of who attended is shown in Table 1 below

Table 1: Number of meetings held with number of attendees in brackets

GP Practice	**Number of Meetings with GPs (number attending)**	**Number of Meetings with PNs (number attending**
Practice A	1(6) 1* (25)	1* (6) 1* (10)
Practice B	1* (2)	1* (3)
Practice C	1* (1) 1 (3)	1 (3)
Total	**5**	**4**

Meetings denoted with * served as focus group interviews at the start of the project.
The CI and PI have also taken part in a number of ad hoc meetings throughout the project to engage with relevant stakeholders including colleagues at:

- Nottingham City Public Health
- East Midland's Suicide Network
- The CLAHRC
- E-DASH Project
- CAMHS
- Nottinghamshire Healthcare NHS Trust

- The Young People's Managed Innovation Network as part of the IMH

Since the start of the project 16 meetings took place with the PI and young people at Base 51. Three of these meetings were used as dedicated time for the focus groups with the remaining meetings being used to develop the blog site, review self-help materials, design posters and develop ethical approval documentation. A total of 14 young people have taken part in at least one or more of these meetings with an average number of 7 young people attending each meeting.

Scoping Review of the Literature

The aim of the literature review was to: i) identify the latest self-help, and peer support practices in relation to young people who engage in self harm behaviour with ii) particular focus on self-help or peer support usage in primary care settings.

The literature was scoped according to Appendix 8. Electronic searches were completed on 28th January 2015 of Web of Science, incorporating Medline (2003-2015), Social Care Online (2003-2015), PsycINFO (2003-2015) and ASSIA: Applied Social Sciences Index and Abstracts (2003-2015). Five principle search terms were used: "young people", "young person", "young adult" ,"self harm", "self injury" combined with "help" "peer" and "primary", with variations and substitutions made as appropriate to the indexing of each database and in accord with the aims of scoping the literature.

Results

Web of Science = 78 results
Social Care Online = 10 results
PsycINFO = 97 results
ASSIA = 21 results

To gather together materials relating to self-help approaches we used a snow-balling approach starting with resources used by Harmless, and through the young people at Base 51 via their creation of the TASH blog site. The RA pursued these leads, searching websites for charitable and public sector organisations and obtained copies of materials published by the national health and mental health charities, and some local initiatives in Nottingham and wider afield in Brighton. A wealth of self-help information and materials was sourced through this process.

The PI shared these materials with the young people at Base 51 some of whom were already aware of the online resources relating to distraction techniques and where to go for help. Young people also considered self-help materials that had been created by the PI for use in the earlier study with women who were self-harming in custody.

Young people decided which materials they considered were most appropriate for other young people in similar circumstances to themselves, trying to manage their self-harm. For example the self-help materials produced by the group in Brighton were preferred by young people at Base 51 above other materials due to the condensed yet attractive format of the information (it was a single, double-sided A4 sheet which folded into a booklet).

A selection of materials, chosen by the young people were then collated into packs designed to be used by GPs and other primary care professionals when they encountered young people who were engaging in self-harm in the surgery.

Baseline Audit of Primary Care Patient Records

A baseline audit of primary care records for young people between the ages of 16-25 who were given a primary diagnostic code for self-harm at each of the three practices was conducted. This revealed a total of 296 young people across the three GP practices which equated to 649 events relating to both physical acts of self-harm and thoughts about self-harm; of which 171 events were not given a specific clinical code. The average number of events for the young people was 2.2 (mean). The most frequently occurring number of events of self-harm across the sample was 1 (mode).

A breakdown of the numbers of young people across the three GP practices are shown in Table 2.

Table 2: Number of young people with self-harm in each GP practice

GP population	**Number of males**	**Number of females**	**Total number of young people in the population**
Practice A	46	129	175
Practice B	17	57	74
Practice C	23	24	47
Totals	86	210	296

The total number of patients reported in Table 2 did not include those who had left the practice or are deceased.

Demographic information about the sample of young people's records included in the audit revealed that of the 296 young people, 86 were male and 210 were female. Table 3 shows a further breakdown of the young people by gender and ethnicity which reveals that the largest group was British or mixed British which accounted for 59%.

Table 3: Young people by gender and ethnicity

Patient Demographic	Practice & Gender						
	Practice A		Practice B		Practice C		Totals
Ethnic Origin	Female	Male	Female	Male	Female	Male	
(not disclosed)	14	4	6	3	2		29
African	2	1					3
Bangladeshi or British Bangladeshi	1						1
Black British		1					1
British or mixed British	68	28	30	8	21	20	175
Caribbean	1		2	1			4
Chinese	1		3	2			6
Indian or British Indian	5	1	6				12
Indian sub-continent (NMO)	1						1
Irish	1					1	2
Other		1					1
Other Asian background	3	1				1	5
Other Black background			1				1
Other ethnic, mixed origin	1						1
Other Mixed background	1						1
Other White background	6	2		1	1		10
Other white ethnic group	1						1
Pakistani or British Pakistani	2	1					3
White and Asian	2						2
White and Black Caribbean	1					1	2
White British	18	6	9	2			35
Totals	129	46	57	17	24	23	296

Table 4 shows the total numbers of young people in each GP practice by problem status. These figures suggests that more young people had self-harm recorded as a past problem rather than an active problem although a significant proportion of young people were not classified according to current or past self-harm.

Table 4: Young people who self-harm currently or as a past problem

GP population	Active problem	Past problem	Unclassified
Practice A	24	97	54
Practice B	8	56	10
Practice C	5	32	10
Totals	37	185	74

Figure 2 and Table 5 provide a breakdown of the types of self-harm by clinical code grouping and exclude any un-coded events. Figure 2 reveals that the number of young people coded for suicide/attempted suicide is small. Overdoses comprise 25% of the events and the largest proportion, (58% of events) were either coded as intentional self-harm/self-harm with sharp object.

Figure 2: Summary of self-harm events by clinical code grouping

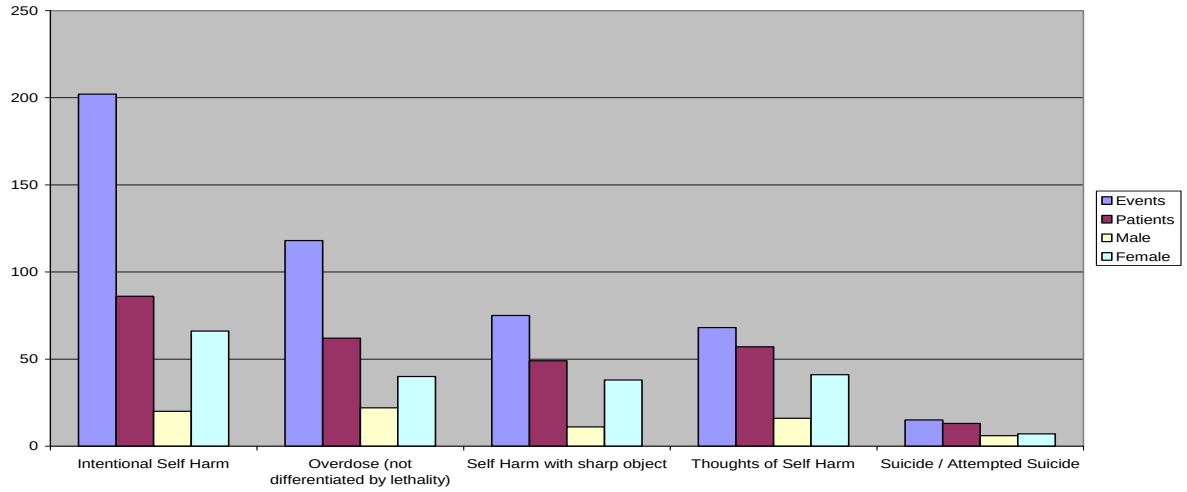


Table 5: Summary of self-harm events by clinical code grouping

Clinical Code Grouping	Events	Patients	Male	Female
Intentional Self Harm	202	86	20	66
Overdose (not differentiated by lethality)	118	62	22	40
Self-Harm with sharp object	75	49	11	38
Thoughts of Self Harm	68	57	16	41
Suicide / Attempted Suicide	15	13	6	7
Totals	478	267	75	192

Of particular interest was the age at which young people were identified with their self-harm issue given the discussions with stakeholders who were concerned that young people were presenting at an even earlier age than perhaps they had seen previously.

Figure 3 shows the percentage of young people by practice with at least one first episode of self-harm under 16 years:

Figure 3: Summary of young people with at least one episode of self-harm under 16 years

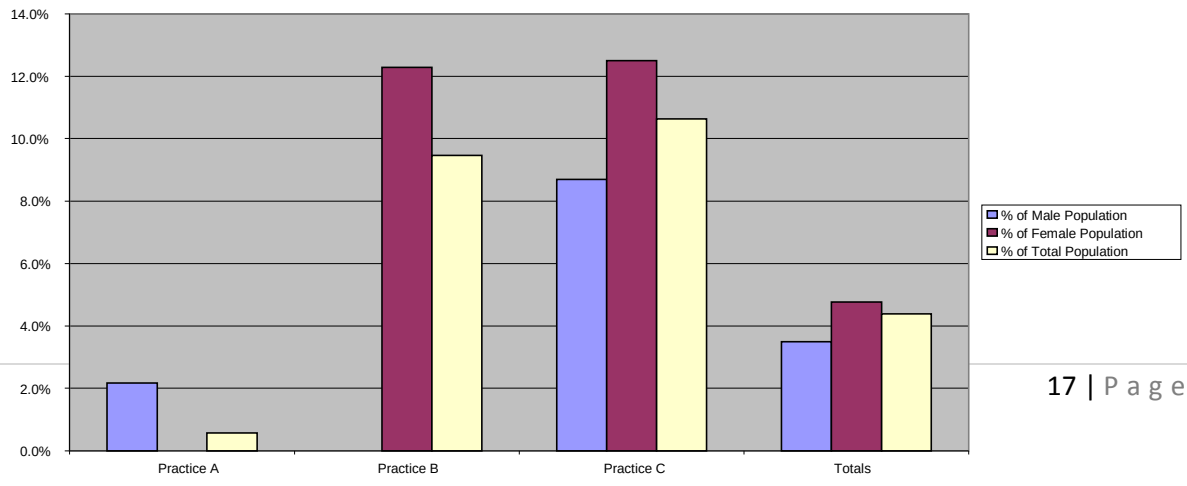


Table 6: Summary of young people with at least one episode of self-harm under 16 years

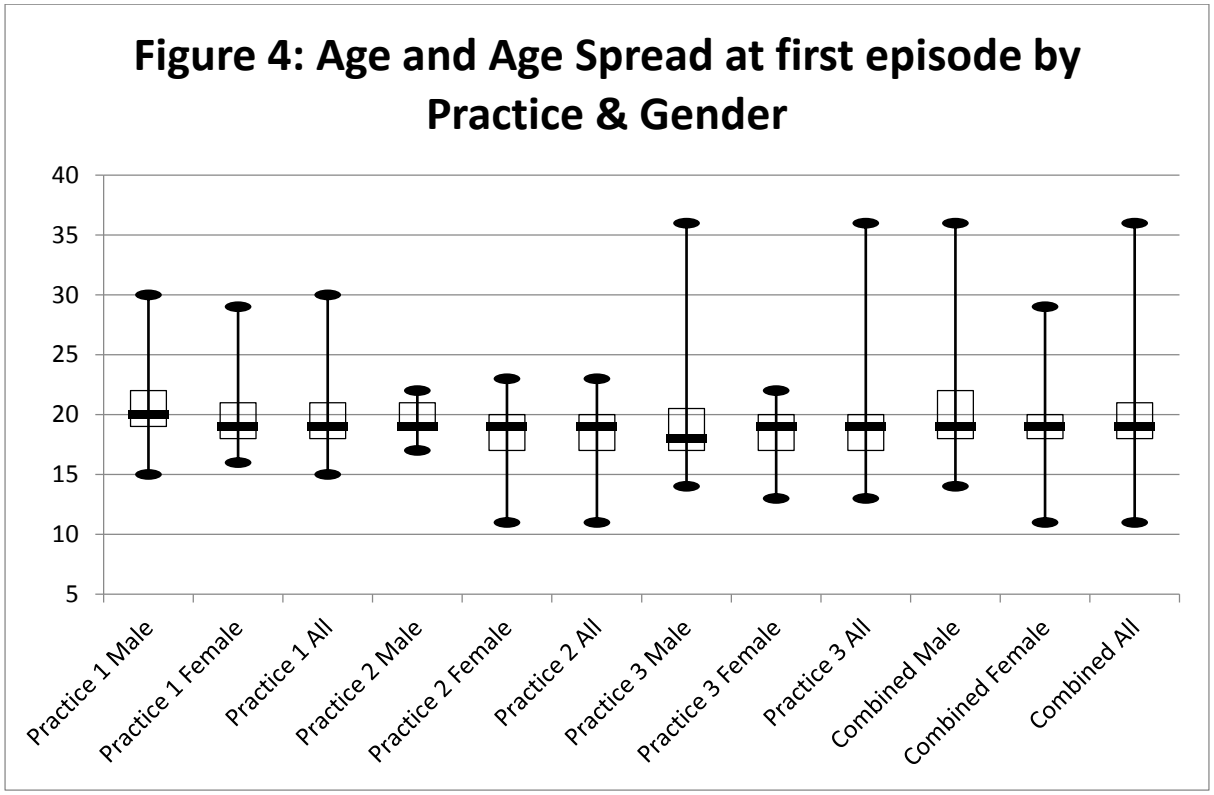
GP Population	% of Male Population	% of Female Population	% of Total Population
Practice A	2.2%	0.0%	0.6%
Practice B	0.0%	12.3%	9.5%
Practice C	8.7%	12.5%	10.6%
Totals	3.5%	4.8%	4.4%

Table 7 shows the average age of young people at their first episode of self-harm which is expanded on in Figure 4 to show the standard deviation in the age of young people compared with the average.

Table 7: Age and age range of young people at their first episode of self-harm

Practice	Male		Female		All	
	Age	Std Dev	Age	Std Dev	Age	Std Dev
Practice A	20.6	3.10	19.6	2.58	19.9	2.76
Practice B	19.7	1.56	18.4	2.39	18.7	2.29
Practice C	19.2	4.27	18.5	2.30	18.9	3.47

Figure 4: Age and age spread at first episode by practice & gender



Qualitative Focus Group Interviews

Primary Care Staff

Four of the initial engagement meetings shown in Table 1 were conducted as focus group interviews. The aim of these focus groups was to ascertain how young people typically presented to primary care with self-harm and what health professionals hoped to get out of the project.

Three general themes emerged relating to: (1) who the young people saw when presenting with self-harm (2) the types of interventions the health care professionals engaged in with these young people and (3) concerns about what to do when young people did present with self-harm.

A consensus was revealed across all three practices that GPs saw more young people with self-harm than the Practice Nurses however this seemed to be dependent on the type of self-harm young people presented with rather than a deliberate strategy on behalf of the practices to steer young people to particular professionals.

Practice Nurses said they tended to see young people who were attending for other reasons such as blood tests, contraception etc. where self-harm became apparent during these consultations rather than as the main reason for the young person attending. The exception to this was the dressing of, or removing sutures from young people's wounds which had occurred through self-harm. Practice Nurses identified that often the first time they 'noticed' a young person was likely to have self-harmed they were given a perfectly plausible account for the wound or injury. However if the young person returned for subsequent appointments it usually became apparent to the Nurses that the wounds could not have been caused accidentally.

GPs said that they would see young people who had taken an overdose and where ongoing medication for example for depression needed to be prescribed.

Although cutting was identified as the most frequently encountered method of self-harm in young people, Practice Nurses also reported dealing with a minority of young people who were burning themselves. Examples given included cigarette burns and scalds to the skin using a hot water bottle. Interventions most frequently used included dressing of wounds, signposting the young person to Harmless or the University Counselling Service or making a referral on behalf of the young person to Let's Talk. There was a general consensus amongst the Practice Nurses that they never gave out self-help materials and would direct the young person back to the GP if they were concerned about the risk posed by the young person's self-harm.

All GPs and Practice Nurses expressed concern about feeling confident to intervene when young people presented with self-harm. Comments included *"not knowing what to say" "should you ask questions about their self-harm if they don't come with that" "I don't want to open a can of worms"*. One Practice Nurse was worried that she had used humour insensitively with a young person who presented with self-harm. A major concern for all health professionals was being the last professional to see a young person who then went onto commit suicide or pushing a young person too far by probing about the reasons for their self-harm which then led the young person to injure themselves more severely. Several comments echoed the theme "*they are the ones you worry about".*

Young People - Focus Group on their Involvement in the Study

Two focus groups were conducted with a total of 7 young people between the ages of 16-23 to capture their experiences of being involved in the project. Reasons given for young people putting themselves forward to be involved in the study came from their own experiences of self-harm or of knowing others who self-harmed and wanting to offer help to other young people in a similar situation.

"Because I self-harmed, self-harmed in the past….I wanted to help other young people not to do it"

"I've had friends that have self-harmed and I've seen how low they can be ….I just thought that if you can help someone else then it's worth participating"

One young person said it was hard at the start of the project when young people started talking about their self-harm although this didn't deter this young person from continuing to participate.

"I think the beginning was difficult when young people were talking about their self-harm…yes they stopped. I never really talked about it"
Some of the young people had previous experience of engaging in research and so knew something of what to expect.
"I've done a few research things before….like um market research"

"I knew quite a bit because I've done research projects at uni so I've kind of done it myself"

In terms of being involved in the project young people felt that they had contributed their ideas and that as a result of their involvement the materials that had stemmed from the project were more tailored to the needs of young people.

"Like I said my ideas…so that the things that were given out so that they are relevant"

"We put our own points there and just sort of everything we said was taken on board and put to use"

They also felt they had contributed practical strategies that other young people could use to help them to manage their self-harm more effectively.

"Other things to do instead of that, like watch TV, watch a nice movie or spend time with family….drawing and like ….other stuff"

All said that they felt that they personally had benefited from their involvement in the project. These benefits varied from feeling that they were genuinely helping others as well as helping themselves through the experience or skills they had gained which included help not to self-harm.

"I've helped about three people not to self-harm"

"*Doing this project actually helped me for my experience because I'm becoming a teacher so it can give me some experience for children who might self-harm"*

It's been very rewarding. I mean like in one respect it's helped me to help people and in another respect it's helped me to think that I can't do any self-harming anymore"

"To know again that we've helped someone and it's very rewarding knowing that we're doing something worthwhile and we can put it on our CV when we leave college for a new job"

Young people were also asked to reflect on the research process in terms of barriers to their involvement, and whether the researchers could have done anything differently.

"Well you explain things….everything is very, very difficult to understand especially with someone with dyslexia…but you like simplify it, you like read for the whole group to understand in like, English"

The young people were all positive about the way the research had been conducted and the flexibility of members of the research team who had worked with them. All the young people wanted an opportunity to continue to be involved in the next stage of the project or to get involved in another research project.

"Today has been good because you've said we're going to this, this and this…yes you've been very flexible"

"I hope when we've finished this project we can do another project…like a bullying project or something like that"

"Yes I'd like to continue to be involved"

Young People – Focus Group on their Experiences of Going to the Doctor

Once it was established that recruiting young people through the GP practices was not going to be a viable option it was decided to hold another focus group with young people who had been attending the meetings at Base 51. Two of these young people did have GPs who were based in the study practices although only one of these two participated in the actual focus group. Seven young people took part in this focus group.

Reasons young people gave for going to see their GP ranged from *"everything"* to "pills*/medication*" "*discomfort in your body*" and to get a referral for things like physiotherapy or counselling.

Apart from one young person who had a very good experience of going to her GP (her GP was based in one of the study practices) the other young people reported overwhelmingly negative experiences, largely because they felt GPs were dismissive or referred them on.

"They try to get you out as quick as possible. They don't really want to pay us much attention"

"I could go in and see the doctor and it's like they're not very interested in what I want though…she wants to know more about my mum than what she did about anything that I wanted".

"When I try to see my doctor they always refer just send me to a nurse instead of the actual GP which is annoying because he is my GP and he is supposed to be able to see me"

"I love my doctor…my doctor's been good"

Reasons young people gave for not going to the doctor fell into three categories, characteristics young people attributed to their GP, young people's behaviour and the health care environment.

Young people admitted to feeling embarrassed or awkward when they went to the doctor:

"My doctor makes everything awkward"

"My doctor is really creepy"

"My doctor's sexist"

"It's quite embarrassing when you have to talk to them about really intimate things and they're a guy"

However young people also admitted that at times the reasons they didn't go was down to them:

"I'm too lazy"

"It's like a 10 minute walk"

"You might do something for yourself….like ..home… remedies"

The health centre building also featured as a reason for young people not to attend;

"The health centre which quite honestly looks more like a jail"

In relation to their mental health young people were very mixed in their views about whether they would go to their doctor;

Interviewer: "Do you think you would go to the doctor with mental health issues?"

"I would. I do"

"I do go to my doctor about mental health issues….they did refer me to…"

"They said that…I now had to refer myself to adult services…it was sort of not as easy. They kind of put you in that….position now it's you that has to do it"

One young person said they preferred to see their GP rather than specialist mental health professionals;

"I would say that my doctor's better than the mental health services…they're rubbish and I don't think are there to help you…and then I'll see my doctor and it's like she'll talk to me about everything, she'll listen to me and then she'll ring them up [meaning mental health services] until they see me and she'll insist that they help me but otherwise they wouldn't do nothing"

In relation to self-harm the young people were again mixed in their views about whether or not they would go to the doctors. Some had good experiences while others expressed concern about disclosing emotional issues or how they would be perceived;

"They'll think I'm crazy and like I said they'll refer me to a counsellor or something and I don't want to talk to someone about my problems if I was self-harming"

"I was scared to talk to the doctor….I just didn't feel confident enough"

"I'm lucky cause of how good my doctor is. I can go talk to him when I want"

"I'm not one to speak my emotions"

However young people did accept although they might feel reluctant to attend*; "If you did need medication or something then you do need to speak to your doctor"*

Young people offered many suggestions for how GPs and their staff could improve the experience of young people when presenting with mental health/self-harm issues. Most of these suggestions referred to giving more information and the relationship that was created with the young person rather than just prescribing medication.

"Just sort of reassure you that it's gonna be ok"

"No matter what you're going through there is people there that can help but at the same time not just sort of get you in and say what's wrong? and then you tell them that you're having these feelings and then they're just like Ok fill this form in and then you leave"

"There should be a set procedure to be honest like step one…if that doesn't work …two, three four then last resort it's on medication"

"No straight away putting them on flippin' tablets"

"Cause the doctors they try and give you medication too easily though"

Young people said that they would like to be asked their opinions:
Interviewer: *"Is there anything that the doctor could do differently then?"*
"Talk to you"

"Ask how you…your opinions like…if they wanted to avert you to a medication I want them to ask you if it's alright to do that"

Another suggestion was that doctors should take a longer-term approach to understanding a young persons' mental health and that their self-harm may come and go depending on what was happening in their lives;

"They automatically just sort of …give you this piece of paper and tell you to fill it out how you've been feeling in the past two weeks…you don't want to fill out a form…you want someone to help"

"My moods were different I felt happy, happy in myself for some points…sad at other points…whereas the six months before that I was alone, depressed and not just wanted to be around"

Sometimes young people said they couldn't remember things after the appointment and might need additional help to understand what they are experiencing.

"It took me three months just to figure out that I had Asperger's after that appointment ….because I was never told"

"I know that sometimes like my doctor will explain something to me like "this is the problem you've got" and then I'll be at home and I'll be thinking like and someone'll say "how did you go with the doctor" and I'll be like I don't know…I don't remember"

Young people felt that despite their age, (which was often the reason they gave for being dismissed by their doctor) the doctor should take them seriously as knowing best about their own situation;

"Cause you're just young, like how do you know about problems in the world….what problems can you have cause you're what fifteen or something…"

"But no-one knows what's happening at home"

"I mean they could be getting hurt at home…and they need someone to talk to"

When asked how the doctors might use the information the young people had chosen to go into the self-help packs young people wanted this to form part of a dialogue rather than just being given out to a young person;

"I'd say like obviously get them out and look at them with the young person together"

"Yeah not just give it them and let them look at it themselves"

"what if they have some problem reading or don't understand"

"Like it's good if you talk it through with them and then let them have something they can look at at home"

Young people also identified that the following resources would be useful to help young people access help for self-harm;

"Like a list of helplines we can use"
"Like being able to see the counselling people in the GPs...they know who they're going to be seeing …and they can feel more ready for when that appointment comes"
Double and follow-up appointments were seen as very useful;

"Ten minute slot it's quite short and then the doctor feels rushed"

Talking about double appointments *"I think that kind of thing cause then you've got more space and you won't feel rushed through it. I think that's useful"*

"If not everything has been said at the end of the appointment ..you know when they catch up with you"

"Yeah like a follow-up"

"I know that like they have their own family and stuff but it's just a case of just a quick check up …to make sure you're alright"

Coaching Intervention

To date, 7 coaching sessions have taken place across two of the practices delivered by the PI and CI. Coaching appointments in the third practice have been rearranged on several occasions and will now take place during the next stage of the project. The 7 coaching sessions have included 3 with Practice Nurses, 1 with GPs and 2 with GPs and Practice Nurses attending together.

The emphasis of the coaching sessions was determined by the GPs and Practice Nurses from the outset of the project and they have focused broadly on helping them to have more helpful conversations with young people who self-harm and using self-help materials as part of these conversations.

Models and easy to use tools to facilitate young peoples' engagement have also been shared and discussed (see Appendix 9). GPs and Practice Nurses have also attended the sessions, keen to discuss particular situations where a young person has presented with self-harm and they weren't sure what to do or thought that on reflection they could have handled the situation better. This 'sharing' of information and experience has helped the coaching sessions to seem 'live' and 'relevant'. Feedback to the research team regarding the coaching sessions is that they have been very well received and staff are feeling more confident to talk to young people about their self-harm. This will be further evaluated as part of the next stage of the project.

GPs and Practice Nurses have also been introduced to the TASH blog site and some have accessed this during a consultation with a young person presenting with self-harm.

DICUSSION & CONCLUSIONS

This study was founded on the premise as stated in our initial project proposal, that early detection and improved services to children and young people with mental health needs presenting to primary care will afford significant benefits in health and wellbeing outcomes and cost savings to the NHS in the longer term.

In order to demonstrate robust evidence for this premise we will need to conduct a longitudinal study that will allow us to track young people with mental health issues and self-harm in particular over a longer period of time.

What this scoping study has demonstrated is that young people are presenting with self-harm to primary care professionals but that anecdotally this is often when other avenues of support have failed or when young people have a particularly good relationship with their GP.

Despite the challenges of disclosing self-harm as voiced by the young people and working with it effectively as voiced by the GPs and Practice Nurses, there was a commitment to improving care in this area and the role self-help materials could play was seen as important.

Young people indicated that they would be more likely to access support from their GP surgeries if they knew they were going to get a response that took them seriously and was offered over a longer period than through one off appointments. If self-help materials were available they wanted their GP or health professional to go through these with them with an opportunity to follow-up or check that they were ok.

We need to undertake further analysis of the random sample of young people's records we have tracked from through the audit process to understand in more detail whether this more 'continuous approach' is offered by the practices. Analysing these records in more detail will also tell us more about whether young people's methods of self-harm change and whether the reasons for their self-harm are explored in primary care consultations which then determines onward referral routes.

The baseline audit tells us that the number of young people attempting suicide is small which offers some support to the low risk of suicide in young people as found by Hawton et al (2015). We need to understand further whether this group reflects Walsh's (2012) definition of those who "wish to end their consciousness completely" compared with young people who are using self-harm as a consciousness altering strategy to cope with life and live another day.

While we know little regarding the intent of the overdoses recorded in 25% of the young people until we have analysed the random sample of young peoples' records in more detail we do know that the largest group presenting to primary care with self-harm issues are those with intentional self-harm and/or self-harm involving a sharp object. Given the comments made by the Practice Nurses and the GPs this might suggest that the majority of young people with self-harm who present to primary care are more likely to be seen by a Practice Nurse, despite Practice Nurses thinking more are seen by the GP. This was to some extent reflected in the coaching sessions with Practice Nurses who recounted many situations where they continued to come into contact with young people who self-harmed. This reinforces the need to involve Practice Nurses in training and in coaching interventions which have a self-harm focus and are designed to improve young people's access to helpful conversations about their self-harm.

The audit of the 292 young peoples' records confirms that self-harm is a gendered issue. There was some evidence from records collected from Practice A and Practice C practices

that young males who self-harm are likely to span a wider age range than their female counterparts.

A very preliminary analysis of the random sample of the 25% of the 292 young people whose records were audited reveals that thoughts of self-harm occurs at times of stress typically to do with exam stress or family issues. We need to understand more about whether these thoughts of self-harm manifest as behaviour, under what circumstances and whether self-help strategies as opposed to other types of interventions are experienced as useful.

Young people themselves confirm that they are reluctant to talk about their self-harm with health professionals for fear of dismissal or onward referral and this experience is confirmed by Practice Nurses and Doctors who encounter young peoples' self-harm often as a secondary issue in consultations and only after plausible explanations have been given for injuries and a young person perhaps returns for another appointment. The fact that only one young person across all 3 practices came forward to consider getting involved in the study confirms that asking young people to talk about their self-harm carries a significant level of concern and circumspection.

Replicating the PAR approach previously used by Bailey in a women's prison in primary care was a challenge. Whilst the GPs and Practice Nurses engaged well, recruiting young people in the practices did not work despite trying different approaches to do this.

Successfully recruiting young people from Base 51 and Harmless to get involved in the project suggests that the action research approach perhaps works best with a captive audience which can be joined by the researchers. This typified the approach in the prison. Young people explained they have their own reasons for not attending GP surgeries and these reasons may be unconnected to their self-harm, such as laziness, distance, ease of home remedies etc. This raises key questions about how to access young people who are going to their GP surgeries for help with their self-harm and whether young people are better accessed, for example, through youth services or through University Counselling Services. These issues will need to be thought through for the larger scale study.

This leads into a wider question which is whether primary care is the best place from which to offer self-help approaches and if not then how can preventative health care for young people be commissioned differently. If, as young people say they seek help firstly from family and peers, might self-help be better promoted through schools, FE colleges and youth services. Further thought needs to be given to this issue in terms of whether a longitudinal study of self-help for young people who self-harm compares self-help offered through different outlets with primary health care being just one of these.

Despite the difficulties of making self-help strategies accessible to young people, the general consensus from young people who took part in the study, as well as the primary care staff, is that being able to have helpful conversations to help young people manage their self-harm is worthwhile doing. It will be interesting to follow this up through further evaluation of how the self-help materials are being used by the GPs and Practice Nurses and whether this seems to make a difference in the way they are engaging with young people who present with self-harm.

Future Research and Practice Implications

The next steps for this project are to:

- Analyse the audit data in more detail to understand young peoples' journeys into and from primary care
- Undertake the rescheduled coaching sessions in one of the practices

- Conduct the evaluation of the self-help materials as they are being used by GPs and Practice Nurses

The young people are keen to remain involved in the study and so we are already exploring with them how they might be involved in a larger scale application to the NIHR.

We also need to spend more time reviewing the research literature in preparation for a larger scale proposal to examine whether there are ways in which we can garner a better understanding of the heterogeneous nature of young people who self-harm. The literature reviewed and our study to date offers some support for a group of young people who if understood as 'attention deserving' rather than 'attention seeking' can be helped to manage their self-harm more effectively and prevented from needing specialist mental health interventions in the longer term. If we can find an effective way of identifying and following these young people over a longer time frame we would be in a better position to offer evidence to inform clinical commissioning decisions and health and wellbeing comes for young people who self-harm.

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